

Domestic Violence and Individuals with Disabilities: Reflections on Research and Practice

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This article details current research on domestic violence and how this affects individuals with disabilities, including those who have acquired disabilities as a direct result of the abuse. All types of disabilities are addressed, as are the various types of abuse that are perpetrated. Special attention is given to the unique issues of individuals with disabilities, and a call for the domestic violence field to embrace the needs of this 15% of the population. Collaboration and coalition building are noted as essential ingredients in addressing the needs of all members of our communities.

KEYWORDS developmental disabilities, intellectual disability, sexual assault, rape, sexual abuse, institutional abuse, cultural diversity among domestic violence victims, diversity

The domestic violence community is slowly recognizing the devastating effects of domestic violence involving individuals with disabilities. While many aspects of domestic violence are similar among all people, people with disabilities can experience unique forms of domestic abuse related to their disability status. This article discusses the need for broadening the definition of domestic violence to encompass the types of abuse experienced by people with disabilities, reflects on the limited but useful research on this topic, and suggests particular areas in need of future exploration, including domestic violence as a cause of disability, the unique situation of people with intellectual and developmental disabilities related to domestic

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violence, sexual assault prevention through sex education for people with disabilities, disability awareness and the domestic abuse movement, and diversity among people with disabilities.

BROADENING THE DEFINITION OF DOMESTIC VIOLENCE

Domestic violence is generally associated with violence between intimate partners or family members who reside together. However, for individuals with varying types of disabilities, the definition of domestic violence needs to be extended to match the lived realities and cultural differences that exist within the disability community. For example, the definition of domestic violence for people with disabilities ought to also include violence perpetrated by caregivers who may or may not reside with the victim, but have caregiving responsibilities that allow them access to the victim's body, finances, personal information, and other usually private matters. For people with disabilities, such perpetrators of domestic violence may be spouses, domestic partners, children, parents, or other relatives of the individual. In addition, perpetrators of domestic violence against people with disabilities may be personal care attendants hired by an individual or an agency to care for a person in his or her own home, while others may have the role of a staff person at a group home, skilled nursing facility, state hospital, or other congregate living arrangement. As a broader array of people may have access to some people with disabilities, the definition of a perpetrator of domestic violence also must be broader. Also, the types of domestic violence people with disabilities experience can also be more wide ranging, as such actions as withholding necessary medications or refusing to help a person with a physical disability to get out of bed also count as domestic abuse for people with disabilities (see Lightfoot & Williams, 2009b [in this issue]).

Some argue that to widen the definition of domestic violence to include perpetrators who are not family members or intimates demeans the thrust of the domestic violence movement. I argue that, conversely, it names the violence experienced by individuals with disabilities in such a way as to pull away the curtain of this hidden area of life for people with disabilities who are victimized, as well as for the public at large who never think of an individual with a disability as a possible victim of domestic violence by either family members or caregivers.

RESEARCH FOCUS ON DISABILITY AND DOMESTIC VIOLENCE

While individuals with all types of disabilities have been victims of domestic violence, there is little existing research on the topic. However, there are

three research efforts that provide information on the topic. These include the work of Dick Sobsey, focusing on abuse of individuals with developmental disabilities; Margaret Nosek, focusing on women with physical disabilities; and Laurie Powers, focusing on a combination of these. The following outlines their important contributions and discusses the need for future research.

According to Dr. Richard Sobsey, the director of the JP Das Developmental Disabilities Centre at the University of Alberta and head of the International Coalition on Abuse and Disability, adults with developmental disabilities become victims of abuse at rates much higher than individuals who do not have disabilities (Sobsey, 1994). Further, his research shows that most of the abuse is perpetrated by family members and others with a close ongoing relationship to the victim (Sobsey). The perpetrator is often in a position of authority and has the trust of the victim, and perpetrators who are paid caregivers often have the trust of the victim's family. In one study, Sobsey and Doe (1991) found that of people with developmental disabilities who had experienced sexual abuse, 44% of the abuse had been perpetrated by a service provider. In regards to sexual assault, Sobsey (1994) estimated that between 15,000 to 19,000 people with developmental disabilities are sexually assaulted each year in the United States alone. Others have estimated that more than 90% of people with developmental disabilities will experience sexual abuse at some point in their lives and 49% will experience 10 or more abusive incidents in their lifetime (Valenti-Hein & Schwartz, 1995). Other types of abuse that people with developmental disabilities often experience include physical assault, verbal and emotional abuse, and financial exploitation, with neglect being the most common form of abuse.

Dr. Nosek, executive director for the Center for Research on Women with Disabilities (CROWD) at Baylor University in Tyler, Texas, found that women with disabilities are abused at about the same rate as their nondisabled counterparts, but the abuse lasts longer and can be more insidious. When one considers the many ways to harm an individual with a physical disability, such as withholding food, water, or medication, or withholding access to a wheelchair, the opportunities are enormous. The victim with a disability often cannot get to a telephone, cry out for help, or leave the situation. Thus the domestic violence notion of being "trapped" takes on a whole new dimension for people with physical disabilities, who often are literally rather than figuratively trapped. Dr. Nosek's research (Nosek, Young, & Rintala, 1995) showed that of women with disabilities, approximately 62% reported being victims of emotional, physical, or sexual abuse, and were thus about equally as likely to experience abuse as the general population, but the duration of physical and sexual abuse for women with disabilities is much longer than for women without disabilities. Despite this fact, leaders in the domestic violence field have not yet embraced individuals with disabilities as part of their constituency.

In her study, Dr. Powers, at the Oregon Health Sciences University, found that among women with physical and cognitive disabilities, 67% experienced physical abuse in their lifetime and 53% experienced sexual abuse in their lifetime (Powers, Curry, Oschwald, & Maley, 2002). She reported that these rates are approximately twice the rates of the nondisabled population. Reflecting on the work of Dr. Powers, it seems probable that men and women with significant disabilities will report equal vulnerability as children with disabilities. Since vulnerability transcends age categories, it logically follows that vulnerability to abuse would continue throughout the life cycle. The most recent research on abuse of children who have disabilities shows that they are abused at rates 3.4 times that of typically developing children (Sullivan & Knutson, 2000). There is no obvious intervening factor that would lessen the vulnerability as people with disabilities age.

While these three research programs have provided us a good beginning knowledge of the incidence and forms of domestic violence, there is still much that we do not know about domestic violence and people with disabilities. Research is needed to explore how domestic violence differs according to the type or severity of the disability; by ethnic origin, race, language, or geographic settings; and by age, sexual orientation, and gender. In addition, there needs to be future research into the possible intervening factors, such as community or family support, as a mediator for domestic violence. A potential research agenda would be to identify the different types of disabilities and then investigate the vulnerability that the specific disability may bring, noting the effects of race, gender, sexual orientation, location, age, and family support (see Lightfoot & Williams, 2009a [in this issue], for a further discussion of research issues).

FUTURE DIRECTIONS FOR RESEARCH AND INTERVENTION

Based on my experiences in the field and with the recognition that people with all types of disabilities experience domestic violence, there are several directions that I believe should be investigated by researchers and practitioners in addition to the basic research questions discussed above. These include domestic violence as a cause of disability, intimate partner violence involving people with intellectual disabilities, sex education as prevention for sexual assault, disability awareness in the domestic violence community, and the interactions between race and culture and disability.

Domestic Violence as a Cause of Disability

There is some, but not much, discussion of the onset of a permanent (or temporary) disability as a direct result of domestic violence (Plichta, 2001). Since a large proportion of physical violence occurs on or about the head,

blindness, hearing disabilities, and cognitive disabilities are common among abuse survivors. Acquired brain injury (ABI) is a little recognized but significant factor that can result from domestic violence, and also can interfere with domestic violence intervention and treatment. Often the victims do not realize that they have acquired a brain injury, but ascribe their difficulties in thinking, decision making, and other intellectual functions to stress rather than to the physical injury to the brain that has occurred. There needs to be more research into the incidence of ABI and other disabilities as a result of domestic violence, as well as awareness by the domestic violence support network that people experiencing domestic violence may also be experiencing a newly acquired disability. The development of necessary supports is imperative for domestic violence professionals to help identify and provide appropriate interventions to people with such newly acquired disabilities.

Domestic Violence and People with Intellectual or Developmental Disabilities

There is also a need for more attention on domestic violence involving individuals with intellectual or developmental disabilities. Most people with an intellectual or developmental disability live with some level of supervision by their parents, another family member, or an agency, and many live either with their parents or in a segregated group home. Dating is difficult, at best, for adults with intellectual or developmental disabilities living in these situations, with limited transportation and the ability to meet each other socially severely compromised. The assistance of support persons (family, friends, or paid staff) is often required to interact, which itself compromises intimacy opportunities. In this author's experience, the situations of intimate partner violence most often encountered by people with intellectual or developmental disabilities are acquaintance or dating violence.

While marriage is still relatively uncommon among people with intellectual or developmental disabilities, even those who do marry often have extensive support from their parents, and may live with or near one set of parents. Parents of married adult children with intellectual or developmental disabilities or adult children in dating relationships have to straddle a difficult line between allowing autonomy to the couple, particularly to work out differences that occur in all relationships, and intervening to ensure the emotional and physical safety of the couple. A stronger focus on providing support to people with intellectual or developmental disabilities and their families or caregivers to navigate these relationships can help prevent domestic violence in this population. Future research should focus on the nature of domestic violence within these relationships and the provision of support that allows for autonomy, yet prevents abuse.

Sexual Assault Prevention Through Sex Education

Although sexual assault among people with disabilities occurs less frequently than neglect, emotional abuse, or physical abuse, its impact can be much more long-lasting and severe. In my experience, acquaintance violence occurring between two people with disabilities most often occurs in the context of the naiveté of the victim and the relative sophistication of the perpetrator. In other words, the individual forcing the sexual act may be another person with a disability who has not gained consent for the actions pursued. The victim, usually a woman, has not understood what he has wanted and has given her consent to much less than was assumed. Then he is on the path to sexual intercourse, while she is overwhelmed, confused, and unable to stop what has begun. He did not, in the moment, recognize her need to stop, nor did he recognize her emotional state. What is required is open discussion of how to gain consent between people with disabilities in regards to intimacy: say what you want and ask if the other person wants the same thing. This process is not necessarily difficult, but when teaching about the niceties of sexual activity has not occurred, date rape can be the result. The victim, without an understanding of what the man wants to do cannot really consent, and thus becomes a victim of sexual abuse. Although there may not have been intent to cause harm by the perpetrator, the victim still feels devastated.

Sex education is essential for preventing sexual abuse among people with disabilities, and it is most often not provided by family members or service providers. Also, when sex education is provided, it is often inadequate for individuals with disabilities for a number of reasons. First, many sex education programs that are geared toward people with disabilities are based on explaining how to say “no” to sex, which is also not helpful to adults with disabilities who are dating or in relationships. Other sex education programs are comprised mostly of anatomical and physiological facts rather than relationship issues. While knowing the physical process of sex can be important, navigating relationships and emotions is as important for people with disabilities. Unfortunately some sex education programs mix sexual assault into sexuality education, creating further confusion as to what is a healthy sexual relationship and what is abuse. Sexual assault prevention should be a different course than sexuality education to avoid suggesting that sexualized violence is normative, or that all sexual intimacy is violence. Finally, for many people with developmental disabilities, whose lifestyle may differ from the standard educational approach, traditional sex education formats may not be appropriate, either in presentation format or topical areas covered.

Research into effective sex education programs for people with disabilities is needed to ascertain which programs are best at preventing future sexual assaults among people with disabilities. In addition, families and

service providers should focus on providing important information regarding consent and other relationships to teenagers and adults with disabilities.

Disability Awareness and Accessibility in the Domestic Violence Movement

Currently most domestic violence literature places little or no attention on the disability status of the survivors of domestic violence (see Cramer & Plummer, 2009 [in this issue]; Lightfoot & Williams, 2009b [in this issue]). While there is an emerging awareness of the incidence involving people with disabilities among the domestic violence community, there is still little awareness of how domestic violence affects individuals with disabilities. This is partially the result of the definitional problems related to the perpetrators of abuse, but also due to the general failure to recognize that abuse occurs among this population.

Domestic violence shelters are, hopefully, beginning to increase awareness of the needs of individuals with disabilities. However, most are neither physically nor programmatically accessible. Most facilities do not have text telephones, accessible entrances, accessible bathrooms, hearing loops, or other adaptive equipment available for potential clients with disabilities. Most domestic violence shelters do not have sign language interpreters available, with most shelters citing financial limitations as their excuse for not complying with the Americans with Disabilities Act (1990).

An exception to this lack of accessibility of domestic violence shelters is Barrier Free Living in New York (Watson, 2001). This facility is the first shelter for men and women with all types of disabilities. Planning for this shelter was extensive and discussions included how to mix individuals with a variety of disabilities, as well as taking into consideration the fact that people live in many types of family situations (single, partner, married, children) and use a variety of assistive devices for mobility and communication. Other programs have begun to strengthen their domestic violence programs at both the state and local levels. Finally, in some locales across the nation, disability service and domestic violence response programs have created alliances and coalitions that strengthen the support that victims of domestic violence receive. One of the best outcomes is that individuals with disabilities are included in the public awareness programs published by these coalitions, helping individuals with disabilities to know that they are welcome at support services agencies.

Research should explore effective ways that domestic violence providers are and could be providing accessible and appropriate services to people with disabilities, either through universally designed shelter services, coalition building between disability and domestic violence services, or through other methods. In addition, the domestic violence community needs to become aware of at least the very basics of the disability community

and disability culture in order to make their services welcoming to individuals with disabilities (see Lightfoot & Williams, 2009b [in this issue]).

Disabilities and Culture

A caveat for the focus on the unique needs of people with disabilities in regards to domestic violence is to recognize that individuals with disabilities are not just individuals with disabilities, but also members of their particular ethnic, religious, national, and other communities. People with disabilities are not monolithic groups, and some forms of domestic violence that exist among people with disabilities may not exist among certain cultures and there may be additional forms of abuse related to disability status among other cultures. In addition, researchers and disability service providers must be aware of the compounding nature of abuse that people of color with disabilities face, and that services may be inaccessible to people by both inattention to their disability and their cultural needs (see Cramer & Plummer, 2009 [in this issue]). Thus the values and cultural distinctions inherent in these distinctions also require sensitivity and knowledge when problems of domestic violence are addressed.

CONCLUSION

There is hope that as the domestic violence movement becomes more sophisticated and begins to build a better research and practice base, it will be able to incorporate other forms of abuse under the umbrella of domestic violence. As the domestic violence movement includes the forms of violence common to people with disabilities under the rubric of domestic violence, it will be better able to provide services to individuals with disabilities. More research in the area of domestic violence and individuals with disabilities will not only help the community to recognize the devastating nature of abuse involving people with disabilities, but also is needed to help develop appropriate and accessible services to this population.

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